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RESEARCH BRIEFING NO. 5

Experiences of hospice and substance use professionals: End of Life Care for People with Alcohol and Drug Problems

“People present with complex and multiple needs including mental ill health and social care needs. The stigma and stereotypical attitudes they face, negatively affect their engagement with health and social care.”

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Key findings

1. This Briefing summarises findings from research exploring the experiences of professionals working with people with problematic substance use (past or present) who are approaching the end of their lives. In particular, it focusses on professionals working in hospice and substance use services.
2. The aims were to i) access the views and experiences of a range of health and social care professionals in delivering end of life or substance use care to individuals and their family members, friends and carers (hereafter, families) where people experienced both issues; ii) assess professionals' attitudes towards supporting people with problematic substance use and chronic or terminal illness; iii) establish the challenges and opportunities professionals face in supporting people with problematic substance use and chronic or terminal illness.
3. Data were collected using a mixed methods approach combining a self-completion survey, focus groups and individual interviews.
4. Both sets of professionals did not find identifying the 'other' issue easy. Hospice staff faced challenges in determining which signs and symptoms related to the health condition or the substance use. Similarly, substance use professionals commented on fluctuating substance use alongside a fluctuating health status making identification of people in need of end of life care more difficult.
5. Hospice staff reported having worked with more people with both issues over the course of their careers than substance use colleagues although this was still a small proportion of their work. They were aware there was an unmet need for end of life care for this group.
6. Practice challenges fell into three core groups: challenges for people with experience of services, challenges for individual professionals and their practice, and challenges for organisations and at a system level.
7. A clear thread through all data sources was the reported complexity and multiplicity of needs that this group of people often present with including mental ill health and social care needs.
8. Professionals encountered negative and stigmatising attitudes from other health and social care professionals towards this group of people, which had a negative, and sometimes serious, impact on their health and care.
9. The current policy and practice climate of recovery-focussed substance use services presented challenges for professionals working with this group of people who will not 'recover'.
10. Difficulties asking or talking about the 'other' issue was a clear theme across both substance use and hospice groups.
11. There was no routine assessment of these overlapping needs in either service setting, with a lack of confidence or willingness, concerns about appropriateness, and concerns about opening 'Pandora's Box', among the reasons for not doing so.
12. Problematic substance use was seen to divert attention away from appropriate responses to wider health care needs, particularly from primary and acute care services.

13. Professionals reported a lack of clear pathways for this group of people to access the services they need and to effect a positive multi-agency response.
14. Symptom and pain management was a major challenge for hospice professionals in particular. Concerns included over- and under-prescribing pain medication, the misuse of pain medication by the individual or their family and friends, and people using a range of substances, including cannabis oil, herbs and spices, to medicate their pain without medical staff knowledge.
15. Families and friends of people receiving end of life and substance use services also presented a challenge to professionals due to problematic substance use by family members, the challenges of working with estranged family members and managing family responses to their relative's continued substance use.
16. Professionals identified their own frustration, sadness, emotional stress and concerns about personal safety when supporting people with problematic substance use at the end of their lives. However, they identified positive team support from colleagues as helping them to cope with the strain.
17. At a systems level, the current funding cuts and austerity measures led to pressures on professionals as a result of gaps in services, slow response rates from other professionals, or the ability to provide the service how they felt it should be delivered.
18. While some partnership working was evident, there was substantial variation from agency to agency and a clear lack of agreed care pathways for this group of people.
19. There were a range of training needs identified by professionals to improve their knowledge and confidence, including how to talk to people about their end of life care or substance use needs.
20. There were a number of examples of good individual and agency practice both in terms of practical support for this group of people as well as positive and empathetic attitudes towards them. This good practice needs disseminating widely.

Introduction

This Briefing summarises data from the full research report of the fifth strand of a multi-strand scoping project (Galvani et al. 2018). This strand explored the experiences of hospice and substance use professionals working with people with histories of problematic substance use at the end of their lives. With increasing evidence of an ageing UK population living longer, and evidence of people taking their substance using habits into older age, it is unsurprising that anecdotal evidence suggests end of life care services are encountering more people with problematic substance use within their service. Similarly, substance use professionals working with older age groups (50 years plus) report increasing complexity in health conditions and status. However, research gathering the views and experiences of professionals working in these services is very limited. Our Rapid Evidence Assessment (REA) found only eight papers since 2004 that drew on professionals' perspectives and these were largely focussed on homeless populations or clinicians prescribing pain medication for cancer patients with problematic substance use (Witham et al., 2018). Understanding the perspectives and experiences of professionals in substance use and end of life services is vital to ensure that they are both trained and supported to respond to the needs of this, potentially increasing, group of people. Their experiences will also help to inform policy developments in this area with a view to improving access to good end of life care for people with problematic substance use histories.

Methodology

The aims of this exploratory study were to:

1. Access the views and experiences of hospice and substance use professionals about delivering end of life or substance use care to individuals and their family members, friends and carers (hereafter, families) who are experiencing both issues.
2. Determine professionals' knowledge and attitudes towards supporting people with problematic substance use and chronic or terminal illness.
3. Establish the challenges and opportunities professionals face in supporting people with problematic substance use and chronic or terminal illness.

This was a mixed method study, drawing on two purpose-specific surveys (completed by 41 substance use professionals and 72 hospice professionals), complemented by seven focus groups (three with hospice professionals and four with substance use specialists) and 10 individual interviews (4 hospice focused and 6 substance use). Focus groups and interviews were audio-recorded and fully transcribed for analysis.

For each method two research tools were designed; one to address substance use professionals' experience of working with people who also had end of life

care needs and the other to explore hospice professionals' experience of working with patients who had histories of substance use. The survey contained open and closed questions and yielded some descriptive numeric data along with some explanatory text. The qualitative data were analysed using a technique known as template analysis (King et al. 2012), an approach which provides a systematic and transparent process for identifying themes within qualitative data.

Participation in all elements of the study was voluntary and participants understood that their information would be kept confidential, and that anything that might identify them or their organisations would be anonymised in reporting the study's findings. The study processes were reviewed for ethical compliance by the Manchester Metropolitan University Ethics Committee. Research governance processes of each of the agencies that participated were also followed.

Findings

The extent and nature of professionals' encounters with 'the other' issue

About two-thirds of substance use professionals responding to the survey (63%, 26 of 41) reported having worked with clients who also had end of life care needs, although only two (5%) reported working with more than 10 clients in these circumstances. In contrast, 90% (59 of 64) of hospice workers had worked with at least one patient who had substance use problems and 26% (19) had worked with 10 or more people with overlapping issues. Although numbers of cases were higher for hospice workers, they were aware that they only saw a very small proportion of people in comparison to hospitals and that, while numbers were increasing, there was still a great deal of unmet need.

While the majority of professionals in both groups thought they would usually be aware that a person had both problems, this awareness would usually come through referral information or reports from the individual or their relatives. Without such pre-existing knowledge however, very few professionals in either group thought it was easy to identify the 'other' problem. Substance use respondents indicated that physical signs of ill-health and poor mental well-being would make them think about the possibility of someone approaching end of life. For hospice respondents it was the physical and mental health manifestations of substance use would be likely to alert them to any substance use problems. They also indicated that behaviour, particularly aggressive behaviour, might be an indicator. For hospice workers the challenge was disentangling the symptoms of substance use with symptoms of the person's end of life health condition and being able to medicate the person appropriately.

In terms of joint working, only a small percentage of professionals from each sector had worked with or referred to the 'other' service. There were mixed experiences from those who had about whether or not the other service had

met the needs of the person referred. The lack of a clear pathway was highlighted for people needing or wanting both services.

Examination of professionals' knowledge and attitudes using adaptations of a standard tool¹ indicated that both groups of professionals felt they did not have adequate levels of knowledge about the 'other' issue, although both groups felt that asking about it was legitimate in their role and that they could find adequate support if needed.

Challenges for the person with experience and for the professionals working with them

Overall, the data from this study suggest that people who have a history of substance use may face particular challenges when they are nearing end of life.

A clear thread through all the data sources was the reported **complexity and multiplicity of needs** that this group of people often present with including mental ill health and social care needs. Their physical health is likely to be marred by multiple conditions, which can impact on activities and emotional well-being and impact on people's ability to engage effectively with services that require attendance at appointments. Having a history of substance use on a person's medical record was perceived by professionals in both hospices and substance use services to be linked with **stigmatising and negative responses** from primary and acute care, even when the substance use was a long time in the past. This resulted in a lack of identification and response to the person's wider health needs.

Analysis of the data produced two main themes relating to challenges for individual professionals: i) meeting the needs of the people in the service and ii) working with other services to meet those needs. Bracketed under the main theme of meeting people's needs were three sub-themes:

1. working with people who don't want to stop using their substance of choice,
2. engaging people in treatment pathways, and
3. the importance of a professional relationship

The challenge associated with working with **people who don't want to stop using** in spite of health harms was writ high in the testimony of substance use professionals in particular. This links, to some extent, to the current policy focus for substance use services that prioritises 'recovery' from addiction and the fact that some clients will not recover. Nevertheless, substance use professionals clearly wanted to help lengthen life, and improve quality of life, by supporting people to reduce or eliminate their substance use. Hospice professionals on the other hand, were focused on quality of life at end of life and saw little point in

¹ The Short Alcohol and Alcohol Problems Perception Questionnaire. Cartwright (1979)

encouraging cessation of comforting behaviours providing this didn't interfere with medication regimes.

In terms of **engaging with people with experience**, substance use professionals highlighted the need for persistence and trying to make the service relevant to them. There was consensus that support needed to be holistic and person centred but concern was expressed by substance use professionals about the need for professional boundaries and minimising opportunities for people to become dependent on the support offered. This was especially so in a policy climate, at the time of this study, of reduced funding and reduced service provision.

The importance of developing positive professional relationships with people in services was identified as key to keeping people in services as well as offering them a choice and a non-judgemental service response.

Under 'working with other services' were two sub-themes:

1. working with primary and acute health care
2. working with mental health and social care services

Professionals from both groups recognised **difficulties associated with the practice of general practitioners and hospital consultants**. Both of these clinical groups were criticised for failing to recognise clinical conditions by overlooking symptomatology and attributing health problems to the substance use – even when this was historic – or by failing to consider that substance use might be at the root of some conditions and referring to substance use services accordingly.

Both substance use and hospice professionals also identified **difficulties engaging social care and mental health services**. There was much discussion of working in silos, and issues identified with thresholds, referral criteria and the capacity of other services to respond. Pressures on other services were recognised by participants and some testified to positive experiences of joint working where they had gone the extra mile to make meaningful links with other professionals.

Three other significant challenges for professionals were identified:

- asking or talking about the 'other' issue,
- challenges relating to symptom and pain management, and
- challenges in working with families (or friends).

Difficulties **asking or talking about the 'other' issue** was a clear theme across both substance use and hospice groups. There was no routine assessment of these overlapping needs in either service. Some professionals reported not knowing how to ask or whether it was their role to ask about the 'other' issue. Others reported being happy to talk to people about their substance use or end of life care but either did not feel it was always appropriate to do so or felt they had to choose the right time in their relationship.

Symptom and pain management was a major challenge for hospice professionals in particular and was a clinical and ethical concern that emerged repeatedly from the wider research programme (Galvani et al., 2018). Concerns included over- or under-prescribing pain medication as a result of the person's substance use, the misuse or diversion of pain medication by the individual or their family and friends, and people using a range of substances that professionals were not aware of and thus they were unable to consider possible drug interactions. These included cannabis oil, herbs and spices as well as other substances.

Families and friends of people receiving end of life and substance use services were not always viewed positively by professionals. Some shared information that professionals found helpful in caring for their relative but others presented a challenge due to their own problematic substance use, or their responses to their relative's continued substance use at the end of life. Some family members were angry and frustrated about the continued use while others encouraged their use by bringing substances into the hospice or continuing to use at home around the person who was trying to modify their substance use. Professionals also found it challenging making contact and communicating with estranged family members.

System level challenges

At a system level, problematic substance use was seen to **divert attention away from appropriate responses** to wider health care needs, particularly from clinicians within primary and acute care services. Participants noted a failure to recognise substance use and particularly a failure to refer into either substance use or end of life services.

In the opinion of professionals, while some partnership working was evident, there was substantial variation from agency to agency and a **lack of clear pathways** for this group of people to access the services they need and to effect a positive multi-agency response.

Substance use professionals felt themselves **outside of the loop** on the gold standard framework and only loosely linked (if at all) in multi-disciplinary teams. Their expertise in managing harm reduction was therefore not available to other professional groups. The current funding cuts and austerity measures were perceived to have led to pressures on professionals as a result of **gaps in services**, slow response rates from other professionals, and the ability to provide the service in the way they felt it should be delivered.

Professionals identified a **variety of training needs** including integrated training opportunities with the 'other' professionals. They also clearly had wider support needs resulting from their own frustration, sadness, emotional stress and concerns about personal safety when supporting people with problematic

substance use at the end of their lives. However, they also identified **positive team support from colleagues** as helping them to cope with the strain.

There were a number of examples of **good individual and agency practice** both in terms of practical support for this group of people as well as positive and empathetic attitudes towards them. This good practice needs disseminating widely.

Limitations

The findings set out in this research are limited to the practice and perspectives of the professionals working within the substance use agencies and hospices that took part in the research. However, given the commonalities of experience across the two groups, it is likely that these findings would echo the experience of others in the substance use and hospice sectors. Further, the survey sample for the study was smaller than hoped and therefore comparative statistical analysis was not possible. The majority of agencies that participated were based in the North West of England with one exception based in the Midlands. It is possible that a wider geographical spread would result in different findings. However, the North West region, remains one of the areas with the highest rates of harm relating to substance use.

Summary

This study set out to explore the views and experiences of two sets of professionals supporting people with problematic substance use and end of life care needs; hospice professionals and substance use professionals. Using mixed methods, this study explored their knowledge of, attitudes towards, and challenges of, working with this group of people. While their experience of working with people with both issues has been relatively limited in number, their perception is of increasing numbers of people with both issues in their services, as well as people in need sitting outside services due to resource limitations and barriers to access.

Common to both groups of professionals was their need for greater knowledge of the 'other' issue although their practice shows evidence of good practice as well as areas for improvement. In particular, their knowledge of how to talk about substance use or end of life care was identified as a training need.

The hospice professionals raised particular concerns about prescribing pain medication, particularly opiate based, to people with current or past substance use, as well as their concerns about 'drug diversion' by family members or friends of the person in need of it. Working with families and friends was also seen as largely challenging, particularly where the family member or friend had their own problematic substance use.

Also common to both groups was their experience of negative attitudes and poor care from other health and social care professionals towards people with substance problems and end of life care needs. Such stigmatising and stereotyping was seen to overshadow the health needs of individuals presenting for care and divert attention away from their genuine health needs.

In contrast, the care provided by the hospices and substance use services represented in this study appeared to show a much more holistic and non-judgemental approach to a person's substance use at the end of their lives. This holistic approach along with increased partnership working and clear care pathways were the particular areas for improvement stemming from this strand of the study.

Conclusion and implications

Professionals working in end of life care and substance use services face increasing challenges from what they perceive to be a growing group of people with problematic substance use and end of life care needs. In the main, they showed initiative, resilience and good practice in an area of practice for which there is little guidance. They also experienced a host of practice challenges, policy gaps, and the frustration and emotional stress of supporting people with problematic substance use, and their families, at the end of their lives. Both sets of professionals operate a non-judgemental approach, in general, towards people with substance problems. At the same time, they have had to witness, and advocate against, the negative and stigmatising attitudes from other health and social care professionals towards the people they support. Policy and practice development could helpfully support these professionals to build good practice at the same time as addressing the inequalities in access to end of life care for people with problematic substance use.

Implications for practice

The learning from this strand of the project suggests that, in order for improvements to be made, practice managers need to:

- offer training and practice guidance at an individual and organisational level about working with these overlapping issues. This would include how to talk to people about the 'other' issue. Integrating training with other specialists would be ideal.
- develop effective local partnership working protocols between substance use and end of life care agencies to support both sets of staff in responding to challenges as they arise.
- ensure that staff within substance use services in particular, are supported in their work with this client group.
- work towards better partnership working with other agencies, such as mental health and social care.

Implications for policy

Developing policy at different levels will support professionals and agencies working with people with using substances at the end of their lives. Further policy work should include:

- Development of organisational level policy on working with people with overlapping end of life care needs and substance use. This should include policy decisions on access to services for this group of people, routine questioning, recording and monitoring, appropriate responses, joint working and referral practice, to name a few. It should be accompanied by practice guidance and training as appropriate.
- Development of local and regional level policy bringing together substance use and end of life care agencies and relevant front-line partners to work

towards a policy framework which is responsive to local needs and considers current funding and service pressures in seeking ways forward.

- Contributing to national level policy debates around end of life care and substance use, particularly with a focus on health inequalities and access to services.

Implications for future research

This was an exploratory study with a purposive sample of hospice and substance use agencies. Future research needs to:

- Develop, roll out and evaluate a gold standard model of care for working with people with problematic substance use and life limiting conditions, including clear care pathways. This will help to determine how to improve access to end of life care for people with problematic substance use.
- Research the experiences and perspectives of a wider group of health and social care staff towards people with problematic substance use and life limiting conditions. Given the findings of this research, this should include primary and acute care staff.
- Scale up the research conducted here to include national populations of staff working in both substance use and hospice services. This was a purposive sample only and a larger sample would determine whether this was an accurate picture of the experiences of end of life care and substance use services.

Further Information

- We thank the Big Lottery Fund for funding the research.
- Our programme of research on *End of Life Care for People with Alcohol and Other Drug Problems* has six strands. This Briefing summarises Strand 5, which aimed to investigate the experiences of two groups of professionals working with people with problematic substance use at the end of their lives.
- We thank all the professionals who gave up their time to participate in the survey, interviews and focus groups, and our partner agencies for supporting this research from the outset.
- For further information please contact Professor Sarah Galvani, s.galvani@mmu.ac.uk

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